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ABSTRACT

The newsletter article provides parents of children with disabilities guidance on finding a doctor, communicating effectively with him, seeking a second opinion, and accepting responsibility in their special child's patient-doctor relationship. The article identifies both formal and informal methods of finding a doctor and gives suggestions for the initial interview. This report encourages parents to become as knowledgeable as possible about the disability, to refrain from withholding any information from the doctor, to keep good medical records, to follow the doctor's orders, and to ask questions. The article also recommends seeking a second opinion, but advises against doctor shopping. The report cautions parents about demanding new or controversial medical treatments. Finally, the report mentions some specific do's and don'ts including "Do ask your doctor to connect you with other parents of children with similar handicaps;" "Don't be afraid to ask questions;" and "Do ask for the last appointment of the day if you wish extra time." (DB)

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Special Parent ★Special Child

Practical pointers for parenting handicapped children

VOL. 5, NO. 2 MARCH/APRIL 1989

YOU, YOUR SPECIAL CHILD AND THE DOCTOR

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D. Murphy

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

The parents of special children more than others are apt to seek medical advice for their offspring. Often their child's disabling condition is chronic in nature which necessitates frequent evaluations and periodic review of prescription drug dosages. Inborn or genetic conditions often manifest themselves in an array of physical symptoms requiring medical intervention. Common childhood illnesses or fevers which ordinarily pose no threat can often complicate any preexisting conditions the special child might have. Special parents frequently find themselves in a quandary—not just any doctor will suffice when it comes to managing their disabled child's medical needs.

In this issue we will focus on finding a doctor, communicating effectively with him, when to seek a second opinion and, above all, what the parents' responsibility is in their special child's patient-doctor relationship.

Finding a doctor

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There are both informal and formal methods of finding the right doctor for you and your child. Often new mothers will ask their obstetrician to recommend a pediatrician. In the case of the special child, the family physician might be asked to suggest a colleague who is perhaps better equipped to care for disabled infants and children.

Asking parents who have children with similar handicaps is another informal method.

If your child's disability has been diagnosed at birth, it's often a good idea to ask the attending doctor or medical center where the diagnosis was made if there are pediatricians who specialize in monitoring this specific disorder.

Other more formal contacts that can be investigated include:

- county medical associations
- university or teaching hospitals
- medical centers or clinics
- your local school district
- parent groups (some compile lists of doctors and specialists)
- agencies for the handicapped

Once you have gathered a suitable list, ask yourself if location is a factor. Traveling long distances

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might prove cumbersome. What hospitals or centers is the doctor associated with? Is it convenient for you to get there, especially in an emergency? Once the logistics are settled, the next step is to arrange a get-acquainted appointment.

The initial interview. Often people are intimidated by the medical profession; this is a sensitive issue when the patient in question is their own helpless child. Knowing this should help ease any nervousness you might feel. Nevertheless, here are several factors to consider during the first appointment:

1. Do you like the way the doctor relates to your child? Is he able to set both of you at ease? Is the "chemistry" right, striking an appropriate chord that you find reassuring?

2. Does he answer your questions in language you understand?

3. Does he listen to you willingly without patronizing you or discounting your opinions?

4. Is he interested in your child as an individual, questioning you closely about all aspects of your youngster's past history? This should include your child's developmental milestones, eating and sleeping patterns and other habits. If your child is school age, the doctor should show considerable interest in how well he does at school and what his hobbies and interests are. This line of inquiry and gathering of information is extremely important in the case of the special child because often regression or changes show up in these areas before there are recognizable physical symptoms. For example, a child with a convulsive disorder who ceases to perform well at school may be reacting to neurological changes and might need a change of medication or even some diagnostic tests. The doctor's ability to make these medical decisions should thus be based on his in-depth knowledge and sensitive analysis of the child's total picture.

5. Don't be embarrassed to ask the doctor about his training or credentials. Most doctors are perfectly willing to share with you details about their background or specific expertise.

6. The first interview is also a good time to have a frank discussion of finances. Find out what the doctor's fee structure is and, should you decide to choose this particular doctor, discuss what method of payment is best.

Finally, don't become dismayed if the doctor does not match your expectations. You might have to search longer to find the doctor you feel best meets the needs of both you and your special child. If, on the other hand, the doctor in question is considered a leading expert but you find his bedside manner deficient, ask yourself if you can learn to live with that. Perhaps there are some ways you can let him know you are an informed parent. See if it is possible to set up guidelines so that your involvement will enhance your child's medical care.

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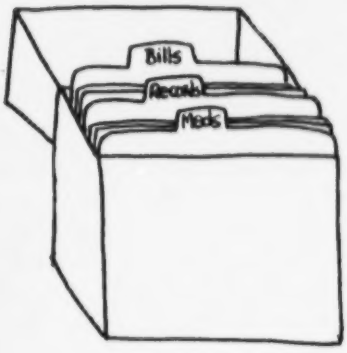
Communicating with your child's doctor

The best time to talk with the doctor is during your child's regularly scheduled appointment, specifically set aside so your doctor can concentrate on just your youngster's needs. Unless there is some medical urgency it is counterproductive to interrupt the doctor during office hours when he is with other patients and is unable to focus on your child. By the same token it's best to use the appointment you have been given as wisely as possible. Jot things down ahead of time so you don't forget some important piece of information or question you might have. Come prepared with an agenda or some factual observations such as a log or diary. This will prevent haphazard comments such as "I don't think the new medicine agrees with Johnny." If your log, for example, describes with some accuracy Johnny's reactions, pinpointing the time, duration, etc., your doctor will be better able to act on that information.

Even more importantly, your doctor will listen to you with genuine respect and appreciation. Take the time to listen carefully to your doctor's advice, comments and instructions. If at all possible, leave your youngster with someone in the waiting room for a few minutes so you can give undivided attention to the doctor. This assures that his instructions can be followed without confusion or error.

Mutual acknowledgement and respect for each other's role is vital if your child is to receive quality medical care.

Parental responsibility



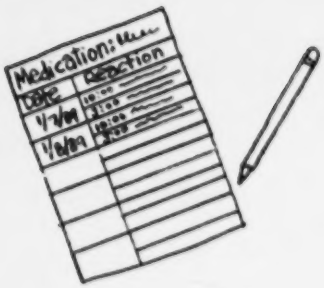
The primary responsibility you have as the parent of a disabled child is to **become as knowledgeable as possible** about the nature of the disability. Read books and articles, attend lectures, become involved in a parent group.

Having a basic fund of information maximizes your ability to understand the terminology and course of medical treatment prescribed for your child. This knowledge will enable you to follow the doctor's orders wisely and in all probability will minimize the actual time spent in doctors' offices. Your expectations of what your child can and cannot do will also be more open and realistic, thus avoiding feelings of disappointment or frustration. Chances are your child's doctor will view you as a more active participant and as a member of the team.

Withholding information from the doctor only serves to impede treatment. Often parents are embarrassed or ashamed about their child's condition and deny or obscure the facts, or don't reveal a previous diagnosis or course of treatment. Perhaps they feel they are at fault and wish to avoid this. However, the doctor needs to know everything in order to treat your child competently. Your omissions could well be a missing piece of the puzzle and, by deleting information, you could jeopardize your child's health and well-being needlessly.

Keeping good medical records is another aspect of the parents' role. In the maze of medical care, records are often lost, X-rays or scans misplaced and doctors' reports can go astray. It is, therefore, up to you to have the following in a safe place:

- names, addresses, telephone numbers of all doctors,



clinics and hospitals where your child is known and the dates of treatment
- record of immunizations
- X-rays, tests
- medical reports and evaluations
- records of medications, current and past, and their dosages
- allergies, drug reactions

Having accurate records is especially important if your child's condition warrants visits to a variety of specialists. Good records will enable the doctors to evaluate what has been tried in the past and has proved to be of no avail.

Following doctors' orders makes good common sense. This is especially true when it comes to administering prescription drugs. In order to take effect, most drugs need to be taken on a consistent basis. Your doctor knows more about each drug's cumulative effect and what therapeutic levels are necessary for the drug to be of maximum benefit for your child. You should never increase or decrease the dosages or discontinue any prescribed drug without discussing this with your child's doctor first. If you feel the drugs are making your child drowsy, irritable, hyperactive or ill, consult with your doctor and ask for a medication review. When your doctor prescribes a particular course of treatment which might include, for example, a special diet, medicines, using special appliances or devices or consulting with other specialists, it's also up to you to follow through.

Ask questions. It's your responsibility on behalf of your disabled child to understand what is expected. If you don't completely understand the doctor's orders, ask for clarification. Nothing is more damaging than parents who nod yes when in reality they are confused. Perhaps the doctor is using unfamiliar terminology or is too vague or unclear. It is **your** responsibility to find out exactly how to proceed or run the risk of unknowingly undermining your child's health.

Seeking a second opinion

If, during the course of your child's medical treatment or care, you decide you want a second opinion, the best option is to discuss this frankly with your child's doctor. Disagreements or differences of opinion over your child's condition or even the desire for someone with a fresher outlook should be discussed openly and honestly. Tell your doctor you wish to have a second opinion. Doctors are human and will often concur that someone else's evaluation is of value. Often a second opinion, especially one that corroborates the current course of treatment, results in greater confidence. However, if the second opinion differs, your current doctor might appreciate this insight and want to pursue the new treatment. If, however, you feel you must change doctors, discuss this with your current doctor. In many cases the doctor will agree that another practitioner is indicated.

This does not mean you should fall into the habit of "doctor shopping," or going from doctor to doctor, clinic to clinic in the expectation that someone holds the key to your child's recovery. Precious time and finances are wasted as different doctors record your child's history, collect and evaluate

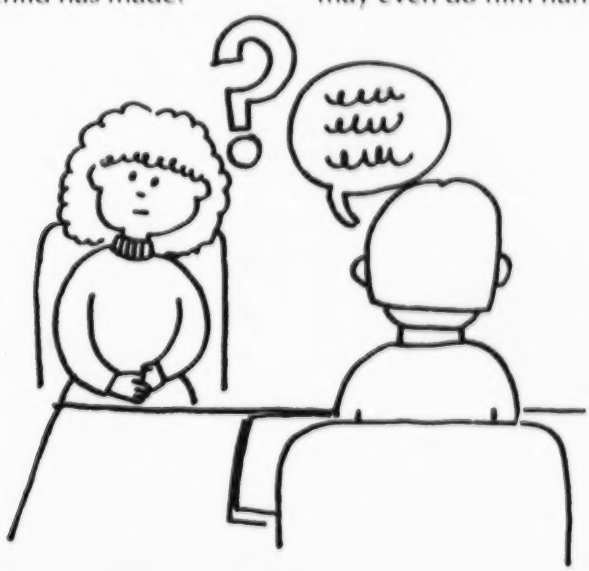
your child's medical records, call for more tests. Care is likely to become erratic and piecemeal and there is always the danger of falling into unethical hands.

Parents who persist in doctor shopping run the risk of having a child who sees himself largely in terms of his disability, or as a medical problem. Frequently, nonacceptance of the child's disability, even guilt are the motivating factors behind doctor shopping. Parents who demonstrate this behavior are wise to seek professional counseling or attend parent meetings where they can share their feelings with others in similar situations.

The treatment dilemma. Often new or controversial medical treatments, promising dramatic improvements, receive widespread media coverage. It is quite understandable that many parents, not wishing to leave any stone unturned when it comes to helping their disabled child, will be tempted. This places the parent in the dilemma of distinguishing between a genuine medical breakthrough and what might turn out to be an unjustifiable procedure that could jeopardize whatever health gains their child has made.

Here are some things to consider before undertaking any new course of treatment. Ask your child's primary doctor what he thinks. If your doctor disagrees, find out why in terminology that is clear to you. Check with your local medical association to see what their position is. If possible, talk with other parents whose children have undergone the treatment. Ask them about duration, side effects and if there were any lasting improvements. Consult with another doctor and see if his opinion differs from your primary doctor's. Most insurance carriers welcome second opinions because objective recommendations are highly valued.

Be wary of any treatments not covered by health insurance. Find out from your carrier the specific reasons this particular treatment has been excluded from coverage. Perhaps there is a good reason that you should know about. Ask the treatment program or doctor for references such as research papers published in reliable journals. Don't make decisions hastily or find yourself pressured into subjecting your child to a course of treatment that might not work and may even do him harm.



Do's and don'ts

Do ask your doctor to connect you with other parents of children with similar handicaps. Other parents can be of great support, and can frequently tell you what to expect.

Don't be afraid to ask your doctor questions about any aspect of your child's care. Make sure your doctor responds without confusing professional jargon.

Do expect to hear from your doctor "I don't know," but make sure your doctor offers to find out, make inquiries or lead you to the right specialist.

Do expect your doctor to listen closely to what you are saying. Remember you are an expert in your own right.

Do keep appointments. The doctor's time is valuable and getting to appointments on time is a good way of creating an effective relationship based on mutual respect.

Do ask for the last appointment of the day if you wish your doctor to take extra time with you. Sometimes you might want to pursue a lengthy discussion with the doctor and he cannot respond adequately because of the pressures of the day, or other waiting patients. Let him know in advance of your request so that he can prepare his schedule.

Don't lose hope. Remember that children frequently make gains despite grim prognosis.

PSYCHOLOGIST'S CORNER:

Coping with fear of doctors

by George Popper, Ph. D.

Going to a physician can be a very stressful and frightening event for a child. The doctor's waiting room may have cheerful pictures and coloring books, but it also has screaming babies and nervous mothers. From the child's point of view, a physician is someone you see when you're sick. Even when the examination is a routine physical some children cannot easily shake the association of the doctor with pain or illness.

The special child's problems are ofen more acute and, in all probability, he receives medical care much more frequently than most children. There are seemingly endless tests and perhaps chronic illnesses of one sort or another that require ongoing attention. After a time, some of these children become used to the situation and seeing a physician is part of their routine. However, there are a significant number of children for whom a visit to the doctor remains a terrifying experience.

Needless to say, all children, whether handicapped or not, require help in dealing with the inevitable visit to a doctor's office. Over the past few years efforts have been made to educate parents and health care professionals about some of the psychological issues involving their younger patients.

Here's how to help:

1. Be as honest as you can without being confusing or overbearing and encourage your child's physician to do so as well. You don't want to completely overwhelm your child with complicated information and details; however, you do want him to have a sense of what will be happening to him.

2. Allow your child to visit with his doctor at a time when he is not ill so they can become acquainted. In that way your child is more likely to feel confident that he is going to someone he already knows.

3. If a visit to the doctor is contemplated, allow your child to know of it about two days in advance. During that time, your child's fears can be addressed and he can be made aware of what will be happening to him then. Some parents are fearful of how their child will react and are inclined to either lie about where they are taking him or don't tell him of the appointment until the last minute. More often than not, this is a mistake. Children are particularly fearful if they feel that others—especially parents—are not being truthful. Your credibility is of the utmost importance. Uncertainties and outright distortions, even if the intent is to protect the child, usually do much more harm than good.

4. Allow your child to participate in his own care as much as possible. Some doctors allow children to help with their examination in small ways. These doctors reassuringly tell children what they are doing, why and whether or not there will be any discomfort. If a child senses that he has some control over what is happening, cooperation is much more likely.

5. Using dolls is a very helpful way to get children to better understand what might be happening to them. Be sensitive to any reactions.

6. If possible, have your child's doctor spend more time talking with your child. Don't ignore your child's fears, but deal with them openly and honestly. Try to help your child understand that you, he and his doctor are all a team.

Medical check-ups for children with special needs

by Neil Stein, M. D.

The editors are pleased to introduce a new contributor, Neil Stein, M. D., F. A. A. P., a physician in private practice in New York and an active member of the Yale Spina Bifida Program in New Haven, Connecticut. Dr. Stein welcomes your questions concerning medical issues and your child.

A regular medical check-up for a child with special needs is basically the same as a check-up for any other child, emphasizing, of course, any area of concern. However, what to include in the check-up, how often to have one and the need for specialists can vary depending on the individual.

The term "physical exam" is misleading because besides routine vaccinations and innoculations, important information is obtained during the interview including the child's medical history, developmental progress and how family members are coping with any problems inherent in raising a special child. The family's medical history should be reviewed as well. Mention should be made of the importance of regular examinations by the dentist.

The goal is to provide comprehensive health care, which can, beside treating illness, prevent some problems and complications from ever arising.

The doctor assesses the child's progress and, depending on the child's situation, may assemble a team of some of these specialists:

- **Orthopedists** specialize in bone and joint problems.
- **Neurologists** specialize in brain and nerve function, e.g., convulsions.
- **Neurosurgeons** are skilled in surgery of the brain and nerves.

- **Physiatrists** are medical doctors who specialize in the mechanics of how the body moves and functions.
- **Occupational and physical therapists** follow the physiatrist's or doctor's orders and plan programs to improve eye-hand-body function.
- **Orthotists** are experts in braces and supports.
- **Urologists** are skilled in treating kidney and bladder functions.
- **Cardiologists** are skilled in treating heart, vascular system functions.

- **Ophthalmologists** are medical doctors specializing in eye problems.
- **Psychiatrists** are medical doctors who diagnose, prescribe medications and/or provide therapy for emotional disorders.
- **Psychologists** are skilled in counseling, testing children's social, emotional, academic functions.
- **Dieticians** are trained to evaluate, plan special diets.
- **Clinical nurses** are skilled in specialized problems, e. g., drug therapy.
- **Speech and language pathologists** are skilled in helping with problems of communication.
- **Education specialists** are certified teachers who can remediate learning problems.
- **Social workers** counsel children and families, make referrals to agencies that can help.

The child's own doctor functions as part of the team and usually deals with all aspects of the child's health whether or not they are related to the special condition. Communication among all the team members is of vital importance. Parents can help by keeping lists of medications and names of all team members up-to-date.

The frequency of visits to the doctor varies with the child's underlying medical condition, but generally visits should be no further apart than every 6-12 months. The specialists on the team may want to see the child more frequently. Changes can occur rapidly in certain cases, and may need to be followed closely.

Your doctor should be considered a resource for information about the child's needs and a valuable asset in obtaining needed sources and supplies. Sometimes parents tend to forego medical check-ups or avoid the medical system entirely, especially as the child grows older and his condition remains unchanged. Resist the tendency. Your child's ability to engage in education, work, have friendships or other social interactions—all these important concerns rest on the keystone of good health.

Illustrations by Leah Spring